



GEORGETOWN UNIVERSITY

*Health Policy Institute*

Testimony of Karen Pollitz  
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on  
Genetic Discrimination in Health Insurance

U.S. House of Representatives  
Committee on Ways and Means  
Subcommittee on Health

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insurability, however, GINA also makes it more likely that the medical benefits promised by genetic science come to pass with the discovery of more effective treatments, cures, and preventive therapies for many serious and expensive health conditions.

Current law prohibitions are incomplete

Congress and the states have already gone a long way toward ending genetic discrimination in health insurance, though work remains to be done. There is not yet comprehensive protection against genetic discrimination in health insurance. Comprehensive protection will prevent all health plans and health insurers in all markets from turning people down, charging them more, or excluding or limiting covered benefits based on genetic information. Only federal legislation can accomplish this goal.

In 1996, Congress enacted the Health Insurance Portability and Accountability Act (HIPAA), setting federal minimum standards for private health insurance, including a requirement that employer-sponsored group health plans may not exclude participants based on genetic information or other factors relating to health status. HIPAA also prohibited group health plans from imposing pre-existing condition exclusion periods based on genetic information. However, HIPAA did not prohibit individual market health insurers from underwriting on the basis of genetic information, nor did it limit insurers in any market from varying premiums on that basis.

Since HIPAA, 43 states have prohibited use of genetic information by individual market health insurers. (See Appendix A) Most have enacted statutory prohibitions, which vary. Some state laws, for example, prohibit medical underwriting based on genetic test results, but not on family history. A few states prohibit insurers from denying coverage based on genetic information, but permit premiums to be surcharged. Interestingly, most state insurance regulators would enforce a broader prohibition on genetic discrimination than plain statutory language might otherwise indicate. For example, most say insurers cannot underwrite based on family history, even when this is not specifically included in the state law definition of genetic information.

young, and relatively few individuals have undergone predictive genetic testing in the U.S. For example, genetic testing for hereditary breast/ovarian cancer via *BRCA1* and *BRCA2* testing is one of the better known and more widely used predictive genetic tests. Since this genetic test became clinically available in the mid 1990s, about 75,000 individuals have been tested through the commercial lab which holds the patents on these genes, and approximately 9,000 have received positive test results.<sup>4</sup> Many, if not most of those patients with positive test results likely were insured by employer-sponsored group health plans, where discrimination based on health status is already largely prohibited.

Even so, as causative genes associated with increased susceptibility to common diseases, such as asthma, heart disease, and cancer are identified, the number of tested individuals will grow considerably. It is therefore important to understand how health insurers would respond to genetic information about applicants for coverage when they encounter this information in the medical underwriting process.

#### Background on Medical Underwriting

Individual health insurance plays a small but important role in our nation's system of health coverage. People often turn to this market when they cannot get health benefits from an employer or when they are ineligible for public programs such as Medicare or Medicaid. In 2005, over 17 million people in the U.S. were covered by individual health insurance, or 6.6 percent of the non-elderly population.<sup>5</sup> On average, over a three-year period, one in four adults buys or seeks individual coverage.<sup>6</sup>

Individual health insurance is medically underwritten in most states. This means applicants for coverage must submit information about their current and past health status – for example, whether they have been diagnosed with medical conditions such as diabetes, dates of and reasons for recent physician visits, names and dosages of recently prescribed medications,

- If offered, the policy may include all covered benefits, or certain benefits may be specifically limited or excluded. For example, the insurer may apply an exclusion rider,<sup>\*</sup> or increase the policy's annual deductible.

#### Underwriter responses to genetic information

Last year, my colleagues and I partnered with Beth N. Peshkin, a senior genetic counselor and associate professor of oncology at Georgetown's Lombardi Comprehensive Cancer, to conduct a study of medical underwriting practices in the individual health insurance market as they relate to genetic information. Our team also worked with private risk management consultants to design and implement this study. This project was supported by a grant from the Nathan Cummings Foundation.

Professional medical underwriters from 23 insurers – some local and some multi-state – volunteered to participate in a survey about medical underwriting practices and genetic information. Survey participants were senior health underwriters from 23 companies that sell individual health insurance. Sixteen worked for national, commercial insurers that write coverage in multiple states; seven worked for nonprofit Blue Cross Blue Shield plans. The size of participating insurers varied, though according to data from the National Association of Insurance Commissioners, three of the participating insurers rank among the top ten health insurance companies based on national market share, and eight rank among the top 25 companies.<sup>10</sup> Participants and their employing insurers were promised anonymity.

Our survey asked participants to underwrite eight hypothetical applicants for coverage. The applicants were arranged in pairs that were almost identical except one person in each pair had received a positive genetic test result. For each pair of applicants, medical information was provided that would likely prompt further investigation by underwriters. The survey noted when

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<sup>\*</sup> An exclusion rider is an amendment to the insurance policy that specifically excludes coverage for a named health condition. Sometimes exclusion riders also eliminate coverage for body parts or systems that a health condition might affect.

tests and assured him the gene variants found are commonly observed in most people.

Survey participants were asked what underwriting action(s) they would take in response to each of the hypothetical applicants. Five of the 23 underwriters responded in seven instances that they would treat applicants differently because of their genetic information. For Brenda, the hypothetical applicant with a BRCA1 mutation, insurers # 7, #8, and #23 said they would, respectively, offer Brenda coverage at a surcharged premium, deny her application, and offer a policy with a rider excluding coverage for all diseases and disorders related to her breasts. For hypothetical Donna, a ten-year breast cancer survivor with a BRCA1 mutation, insurer #11 would reject her application. Insurer #1 said consideration of the application from hypothetical Fritz would be postponed pending provision of additional medical information, while insurer #8 would deny Fritz's application. Finally, insurer #8 would postpone consideration of Howard's application pending provision of additional medical information.

In addition to these actions, in two other instances underwriters (for insurers #7 and #21) were uncertain as to the appropriate underwriting action and said they would need to consult their medical directors. (See Table 1)

The good news is that most underwriters said most of the time that they would not act based on genetic information. Most said this is because their company policy is to underwrite on the basis of a definitive diagnosis and treatment, and they do not underwrite on the basis of family history or genetic information in the absence of a diagnosis. Most underwriters believed their company policy had been adopted pursuant to laws prohibiting this practice. (Those from multi-state insurers said their company's policy would apply even in those states that have not yet enacted legislation.)

Nevertheless, survey findings are also consistent with patient and policymaker concerns that genetic discrimination in health insurance can happen today and could pose a problem in the

consider those pursuant to genetic testing. As part of our research, we asked underwriters to participate in a follow up survey that also tested their reaction to genetic services. The follow up survey sought additional information about one of the hypothetical applicants with a *BRCA1* mutation, who would also have been counseled about options for reducing her inherited risk of breast and ovarian cancer. Underwriters were asked, "If Donna's medical records indicated her doctor had discussed or recommended options to reduce her risk of future breast cancers (for example, prophylactic surgery) what underwriting actions would you take on her application?"

Only 13 underwriters responded to these follow up questions. Of those, five indicated they would take an adverse action in response to Donna's doctor having discussed risk reducing options, while ten of 13 said they would take an adverse action if the doctor recommended a significant medical procedure to reduce inherited risk. (See Table 2) Interestingly, when the same question was posed to state insurance regulators, most said their laws would also protect against genetic discrimination based on these kinds of patient-physician communications. (See Appendix B)

**Table 2. Underwriting Actions for Donna Based on Interventions to Reduce Breast Cancer Risk (Counseled vs. Recommended)**

Insurer	Underwriting Action	
	Doctor discussed prophylactic surgery to reduce risk	Doctor recommended prophylactic surgery to reduce risk
1		Postpone
2	Probably Rider	Probably Rider
4	Rate	Rate
6	Rider	Rider
7		Rider or Deny
10		Deny
11	Deny	Deny
12		Rider
14		
15		
16		Postpone
17	Deny	Deny
20		

were spread across all four applicants with genetic information. One of these respondents expressed uncertainty as to the meaning of one of the genetic tests. Experts in the field of genetics have long called for “vigorous educational efforts” within the insurance industry to improve understanding about genetic information. Findings from this study suggest such education could be beneficial. Comprehensive federal legislation could also reinforce and strengthen state restrictions and promote a uniform standard within the health insurance industry to never use genetic information in medical underwriting.

From the insurer perspective, medical underwriting in individual health insurance is based on a key premise: the insurer promises to cover an individual’s future health care risks, but only if the applicant discloses known risks today. Public policy has insisted on an exception for genetic information – protecting this information, at least partially, because the clinical significance and promise of this science is so profound. Policymakers will have to decide how comprehensive and uniform protections should be. In so doing, they will have to consider the problem of health insurance discrimination in light of what genetic testing means for patients today and what it is likely to mean in the future. Advances in genetic science may make possible dramatic improvements in medicine and public health that can reduce or prevent the incidence of many serious and expensive health conditions. For that day to come, patients will need assurances that they can both learn their genetic status and take appropriate actions to reduce their risk and improve their health without endangering their insurability.



Prohibited Underwriting Action												
State	Application asks about:			Deny coverage based on:			Raise premium based on:			Exclusion rider based on:		
	Family history	Received genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referred for genetic services (incl. counseling or testing)	Positive genetic test results	Family history	Referral for genetic services (incl. counseling or testing)	Positive genetic test results
OH			√			√			√			√
OK <sup>+</sup>				X	X	X	X	X	X	X	X	X
OR	√	√	√	X	X	√	√	√	√	√	√	√
PA	**	**	**	**	**	**	**	**	**	**	**	**
RI	X	√	√	X	√	√	X	√	√	X	√	√
SC				X	√	√	X	√	√	X	√	√
SD												
TN		X	√		√	√		√	√		√	√
TX				X	X	√	X	X	√	X	X	√
UT		√	√	X	√	√	X	√	√	X	√	√
VT				√	√	√	√	√	√	√	√	√
VA				X	√	√	X	√	√	X	√	√
WA	√	√	√	√	√	√	√	√	√	√	√	√
WV												
WI		√	√		√	√		√	√		√	√
WY				X	X	X	**	**	X	**	X	

Source: Statutory research by Georgetown University and responses of state insurance regulators to Georgetown survey conducted in May-June, 2006. Regulators in five states did not respond to the survey: California, Mississippi, New Mexico, New York, and Vermont. In these states, table only indicates prohibitions found in statutory language.

√ indicates prohibition found in state statute.

x indicates state regulator confirms practice is prohibited, but practice is not specified in statute.

\*\* Regulator did not answer this question. No statutory prohibition found.

+ Additional state notes below:

Alabama prohibitions only apply to genetic information about risk of cancer.

Arizona prohibitions unless "applicant's medical condition and history and either claims experience or actuarial projections establish that differences in claims are likely to result from the genetic condition."

Arkansas prohibitions apply "except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk."

California prohibits insurers from denying "enrollment or coverage to an individual solely due to a family history of breast cancer, or who has had one or more diagnostic procedures for breast disease but has not developed or been diagnosed with breast cancer."

Illinois allows an insurer to "consider the results of genetic testing...if the individual voluntarily submits the results and the results are favorable to the individual."

Missouri prohibits insurers from inquiring "to determine whether a person or blood relative of such person has taken or refused a genetic test or what the test results of any test were..." except with approval of the applicant to consider this type of information.

Oklahoma prohibitions apply "except to the extent and in the same fashion as an insurer limits coverage or increases premiums for loss caused or contributed to by other medical conditions presenting an increased risk."



Prohibited Underwriting Action						
State	Deny coverage based on:		Raise premium based on:		Exclusion rider based on:	
	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options	Physician discusses risk reduction options	Physician recommends risk reduction options
OH	X	X	X	X	X	X
OK <sup>+</sup>	X	X	X	X	X	X
OR	X	X	√	√	√	√
PA	**	**	**	**	**	**
RI	X	X	X	X	X	X
SC	X	X	X	X	X	X
SD						
TN						
TX	X	X	X	X	X	X
UT	X	X	X	X	X	X
VT	√	√	√	√	√	√
VA	X	X	X	X	X	X
WA	√	√	√	√	√	√
WV						
WI	X	X	X	X	X	X
WY	**	**	**	**	**	**

Source: Statutory research by Georgetown University and responses of state insurance regulators to Georgetown survey conducted in May-June, 2006. Regulators in five states did not respond to the survey: California, Mississippi, New Mexico, New York, and Vermont. In these states, table only indicates prohibitions found in statutory language.

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